THE SURGEON GENERAL'S WORKSHOP ON SELF-HELP AND PUBLIC HEALTH

University of California
Los Angeles
September 20-22, 1987

INTRODUCTION

Emotional support in times of trouble is a basic need, and human beings have traditionally received it from family and community. But there have been profound changes in the nature of family and community life in our times that have made those sources less available or less reliable for many people. For example, community life can be practically impossible in a society as highly mobile and fragmented as ours. Social changes affecting families and communities, together with the fact that there have always been some problems that simply cannot be shared with either family or the broader community, can create devastating feelings of isolation and hopelessness for people who are ill or in distress.

Many health and other personal problems have no easy remedies, and for some people the problems are lifelong. Increasingly, however, people in need of emotional support for such problems are finding it in groups that are dedicated to helping people help themselves. For literally millions of people, these groups, called self-help or mutual help groups, are providing an effective and rewarding alternative to coping with serious problems all alone. The essence of these groups is that their members help each other cope with or overcome a health or other problem that they all share.

Thousands of such groups have sprung up in communities across the country in recent years, although the history of the self-help movement spans centuries. These groups deal with a vast range of health and other human problems, such as alcoholism, genetic disorders, chronic disabilities, emotional disorders, and bereavement. Indeed, such groups are so numerous, and they address such a wide range of human problems, that numerous self-help information clearinghouses have sprung up across the country to keep track of them all, so people needing help can be referred appropriately. These clearinghouses are also instrumental in helping new self-help groups get started, and new ones are starting all the time.

It has been estimated that a half million self-help groups are serving some 10 million people in the United States. There are probably several valid ways to classify them. The National Institute of Mental Health has identified three general kinds of self-help groups: groups for people with a physical or mental illness, with groups in existence for practically every disorder; recovery groups for people with problems such as alcoholism, drug addiction, or other compulsions or addictions; and groups for certain minorities such as the handicapped. Many of these groups serve not only their primary members but also their families.

Although emotional support is the central purpose of most self-help groups, many of them also engage in advocacy of changes in policies, laws, attitudes, and practices in the broader communities. It is not uncommon, for example, for groups to work for changes in profes-

sional health care practices, because their members perceive from personal experience that the formal health care system sometimes has serious shortcomings in dealing with patients and their problems.

Despite their diversity, the basic purposes of all self-help groups are the same: to provide mutual aid and emotional support for people who share the same predicament. People who have struggled long and alone to cope with a personal problem or tragedy feel great relief and security when they discover others who know exactly what they are experiencing because they are in the same situation. In this accepting environment, where there is empathy, people can express their feelings and know that they are understood, and through mutual help the members can develop more effective ways to cope with the problem they all share. What people discover in self-help groups is that when they help others they help themselves, and that can be a happy discovery indeed.

Self-help groups share some other features as well. One of the most typical features of self-help groups is a strong desire to be autonomous. Although many successful self-help groups have been initiated by physicians or other health professional who brought people with common problems together, they usually have developed spontaneously out of needs perceived by people in their own lives. In either case, a key element of success is that members see the group as belonging to them, although most self-helpers welcome recognition, support, and cooperation from professionals. The relationship between self-helpers and formal systems for health care delivery can sometimes be strained, however. Many self-helpers consider the established health care systems to be insensitive, resistant to needed change, and unappreciative of the unique perspectives and contributions that can be provided by individuals who have experiential knowledge of an illness or other condition.

Self-Help and Health

A growing body of research is demonstrating that social support helps healthy people stay well, speeds the recovery of people who are ill, and improves the quality of life for those for whom full recovery is not possible. The following are examples from recent clinical literature:

- Only 20 percent of patients with emphysema, chronic bronchitis, or asthma who participated in a self-help group needed hospitalization over a 6-month period, compared to 64 percent of controls. The self-help participants who did have to be hospitalized spent an average of 0.8 day in the hospital, compared to an average of 5 days for controls. (Jensen, P.S. Risk, protective factors, and supportive interventions in chronic airway obstruction. *Archives of General Psychology* 40(11), 1983.)
- In a randomized prospective study, women with metastatic breast cancer who participated in a weekly support group had significantly lower mood disturbances, fewer maladaptive coping responses, and less phobia than similar patients who did not participate in a support group. (Spiegel, D.; Bloom, J.R.; and Yalom, I. Group support for patients with metastatic cancer: A ramdomized prospective outcome study. *Archives of General Psychiatry* 38(5), 1981.
- A randomized study of men and women with rheumatoid arthritis found that patients who participated in a mutual support group showed greater improvement in joint tenderness than a similar group of nonpar-

ticipants. The 105 patients in this study were randomly assigned to one of three conditions: a stress management group, a mutual support group, or a no-treatment group. The stress management and support groups, which were facilitated by a psychologist, met for 10 weekly sessions. (Shearn, M.A. and Fireman, B.H. Stress management and mutual support groups in rheumatoid arthritis. *American Journal of Medicine* 78(5), 1985.)

- Forty patients discharged from a State psychiatric hospital who were randomly assigned to a Community Network Development Program (a type of self-help group) had half the rehospitalization rate of 40 similar patients who did not participate in such a program. They also required one-third as many patient days of rehospitalization (7 days versus 25 days) and fewer contacts with community mental health services agencies (48 percent versus 74 percent). (Gordon, R.E.; Edmunson, E.; and Bedell, J. Reducing hospitalization of state mental patients: Peer management and support. In: A. Jeger and R. Slotnick (eds.) *Community Mental Health*. New York: Plenum Press, 1982.)

In addition to studies aimed at objective measurement of outcomes, there have been a number of surveys of participants in a variety of self-help groups organized around physical, mental, and social health problems. Response rates are typically very high, and the majority of respondents report that their participation in such groups has brought them significant benefits.

Although it may seem paradoxical, modern advances in medical knowledge and technology are making self-help groups increasingly important. There is no real paradox, however:

- People with disabling conditions that would have been quickly fatal a generation ago can now live for many years. As a result, more people face the problem of learning how to live successfully and happily despite chronic disability. Many are learning how in self-help groups.
- Research shows that a growing proportion of health care outlays in our aging population are for diseases related to lifestyle, such as excessive drinking, smoking, and overeating. There are, however, no magic elixirs to change someone's lifestyle. Those changes have to come from the individual, but they are often extremely difficult, if not impossible, to accomplish alone. For this reason, health professionals have become very interested in developing closer relationships and referral patterns with self-help groups devoted to helping their members conquer health-threatening habits or chemical dependencies.
- Though advances in medicine in recent decades have been spectacular—organ transplantation, for example—their cost is also spectacular, and they clearly cannot be regarded as general tools to preserve and improve the public health. Health care financing systems are under great strain and are very much involved in efforts to contain costs by stressing prevention rather than cure. Self-help groups focused on healthy living are being viewed increasingly by employers, health plan administrators, and public health officials as an attractive alternative to the costly formal medical interventions that must be made after disease strikes.

These and related trends in public health suggest that the formal health care system, which is traditionally oriented to

treating sick people case by case, cannot by itself be expected to preserve the health and well-being of our people. There is growing recognition that informal care networks perform unique and valuable health services that can have great impact on public and personal health and well-being. Obviously, self-help groups cannot be substitutes for surgery, pharmaceuticals, and other medical interventions. But their approaches can give a human dimension to health care, help people assume greater responsibility for their own health, and simultaneously address the needs of body, mind, and spirit.

Self-Help and Public Health: Steps Toward Partnership

In May 1986, representatives of self-help clearinghouses, the American Medical Association, and the American Hospital Association met with C. Everett Koop, M.D., Surgeon General of the U.S. Public Health Service, to discuss possible ways in which self-help groups and health care professionals could work together for the benefit of public health.

Dr. Koop expressed great interest because he has long believed that self-help groups can play an extremely useful role in preserving and restoring health, and that the self-help movement ought to be regarded as a valuable partner of the formal health care system. In his long career as a pediatric surgeon he had frequently witnessed, long before the phrase "self-help group" became current, the benefits to patients and their families that resulted when they were brought together with others in the same situation.

Periodically, the Surgeon General convenes workshops to address public health issues and solicit recommendations from participants regarding necessary actions. At the May 1986 meeting Dr. Koop offered to sponsor a Surgeon General's Workshop on Self-Help and Public Health. After consultation with constituencies and further meetings with Dr. Koop and representatives from the U.S. Public Health Service, the self-help advocates formed a steering committee to begin the planning process for the workshop, including the selection of a planning committee.

The steering committee included representatives from the American Medical Association, American Hospital Association, U.S. Public Health Service, and the International Network of Mutual Support Centers. Actual preparations for the workshop were handled by the 25-member planning committee, which included representatives from a broad range of self-help organizations. Subcommittees addressed selection of participants, resources development, issues development, and postworkshop activities. Seed money for the workshop came from grants from the W. Clement and Jesse V. Stone Foundation. The California Department of Mental Health, the Exxon Corporation, and the U.S. Public Health Service contributed funds for later activities.

The workshop, held in Los Angeles on September 20-22, brought together nearly 200 leaders in the self-help movement to develop specific recommendations aimed at expanding and strengthening the role of self-help groups in protecting and enhancing the Nation's health.

The workshop participants, selected to represent a broad cross-section of self-helpers, academicians, professional health caregivers, and public policymakers, developed and presented 16 recommendations to the Surgeon General for creating a partnership between the self-help movement and the formal health care system.

This document is the product of their deliberations.

CHAPTER 1

ORGANIZATION OF THE SURGEON GENERAL'S WORKSHOP ON SELF-HELP AND PUBLIC HEALTH

Organization of the Surgeon General's Workshop on Self-Help and Public Health was guided by a planning committee whose membership represented a broad range of self-help and public health activities. The membership included representatives of national and local self-help groups and clearinghouses, health professionals, and researchers.

In planning the workshop, the Committee operated under the following assumptions:

1. As a Surgeon General's workshop on self-help and public health, the primary focus would be on self-help groups as an informal support system whose activities are relevant to public health. Self-help groups dealing explicitly with physical and mental health concerns would therefore be the primary topic of discussion, although it was recognized that many other kinds of informal support systems dealing with issues such as housing, poverty, and unemployment can also have important impacts on public health.
2. For the purposes of the workshop, self-help groups would be defined as self-governing groups whose members share a common health concern and give each other emotional support and material aid, charge either no fee or only a small fee for membership, and place high value on experiential knowledge in the belief that it provides special understanding of a situation. In addition to providing mutual support for their members, such groups may also be involved in information, education, material aid, and social advocacy in their communities.
3. It was recognized that, although self-help groups share many characteristics, they also differ from each other in important ways.
4. Convening the workshop would not imply that self-help groups are in need of enhancement by professionals, governments, or any other outside party.
5. It was recognized that the informal support systems and the formal health care delivery system provide somewhat overlapping functions, but that they have significantly different purposes and neither can substitute for the other.
6. For the purposes of the workshop, partnership would be defined not in the narrow and legalistic contractual sense, but rather as a relationship that is mutually beneficial to people (or organizations) who are interdependent whether they realize it or not. Partnership in this sense can include relationships in which there is friction and challenge as well those where things go smoothly.
7. Exchange of information among self-help groups, health care professionals,

and health care systems was deemed desirable and worthy of encouragement.

The Issue Development Subcommittee, one of four working groups of the planning committee, refined the issues to be discussed at the workshop and collected background information (see Appendix A) to provide a common knowledge base for all participants. Commissioned data collection activities included key informant interviews, surveys of callers to self-help clearinghouses, and surveys of providers in hospitals and health maintenance organizations. Based on the results of the data collection, it was recommended that all eight workshop groups address these two broad questions:

1. How can public health be improved through partnership between self-helpers and the health care delivery system?
2. How can these partnerships be achieved without compromising the essential nature of self-help?

The range of issues addressed at the Surgeon General's Workshop is reflected in a set of specific questions sent to participants before the workshop to stimulate their thinking about the self-help/public health partnership idea:

- How can communication between self-help groups and health care professionals be increased and improved? What are the advantages and disadvantages to the self-help movement in having stronger relationships with the health care professions? Can such relationships be established without violating the traditions and essential characteristics of self-help groups? What are the proper roles of clearinghouses, governments, health care professionals, and researchers in relation to the self-help movement? What things help or hinder the flow of information among self-help groups and between those groups and professionals?
- How should consumers and service providers learn about and gain access to self-help groups? Should self-help organizations develop a massive informal communication system to disseminate health information? How can clearinghouses for referral and self-help group development services be financed?
- How can self-help enhance the effectiveness of the long-term care delivery system? How do self-help approaches affect the course of chronic illness, recovery, and care utilization? What are the positive and negative outcomes of self-help groups?
- How can self-help become a component of a coordinated health care plan? Will pressure for cost containment compromise the quality of care by letting referrals to self-help groups take the place of referrals to needed professional care? Is there a danger that policymakers will use the existence of self-help groups as an excuse to recommend cuts in vital health care services and entitlement programs?
- What factors help self-help groups develop, and what are the effects of external resources on this process? What kind of training is needed for self-help group leaders and facilitators and for professional service providers? What kind of education for the general public? What research and demonstration programs should be undertaken?

Questions like these were very much on the minds of the participants during the two-and-a-half-day workshop, and their answers to them were reflected in their recommendations to the Surgeon General.

CHAPTER II:

OPENING PLENARY SESSION
Sunday, September 20, 1987

WELCOME AND CHARGE TO THE PARTICIPANTS

C. Everett Koop, M.D.
Surgeon General
United States Public Health Service

I am very pleased to welcome all of you to this Surgeon General's Workshop on Self-Help and Public Health, and I am especially happy to see such a large group of participants representing self-help and mutual help organizations from all over the country.

I know that for many of you, coming to this workshop required a considerable sacrifice of money, time, and energy, but I hope your experiences here will repay you a hundred times over. You won't get your money back, I'm afraid, and the time of course is gone forever, though I'm sure the calories you burn here will all be restored. But what I hope you will get from this workshop is the opportunity to renew old friendships with your colleagues and make new friendships with others who, like you, labor long and hard, a day at a time, to help themselves at the same time they help others.

I had a conversation a while ago with several colleagues in the health field back in Washington. We were talking about the self-help movement and the desirability of having a workshop to explore its potential to contribute to public health. One of them asked, somewhat skeptically, "Dr. Koop, do you think it's wise to invest the power and prestige of your office in the self-help movement?" My answer was an emphatic "Yes," because I believe self-help is an effective way of dealing with problems, stress, hardship, and pain. So, I have called all of you together here to spend the next 2 days discussing how self-help and public health can work more closely together toward the common goal of personal well-being. By the final session I hope we will be able to shed some light on the potential contribution of government to the self-help movement, especially how the Public Health Service can acknowledge more fully the benefits of self-help in health care delivery.

We in government need your contributions to help us find the answers to two fundamental questions: What do we want to do? What do we have to know in order to do it well? Now those questions sound simple, but don't be fooled. Getting answers to them is a major challenge for health policymakers, health care providers, and everyone else involved in maintaining and improving the health of Americans.

What do we want to do? When I was in medical school, back in the Dark Ages, I learned how to diagnose and treat patients with a variety of disease conditions. What we wanted to do was cure people, repair their hurt and broken bodies, and sometimes their broken minds. Today, that desire alone is not a sufficient basis for a health care system. Mending people, curing them, is no longer enough. It is only part of the total health care that most people require.

For one thing, people who go to doctors these days do not present, as much as they used to, a clear-cut disease that calls for a highly specific treatment.

According to a recent national survey of physicians' practices, the main reason people go to a doctor is for what has been called "a condition without a sickness." The patient does have trouble of some kind, of course, but it does not fit the traditional disease categories. Medical schools and other health profession schools have not quite caught up with the self-help and mutual help groups who have long recognized this reality. I believe that recognition is a key aspect of the valuable work these groups do.

The anguished parents of a mentally or physically impaired child, the sorrowful child who grows up in an alcoholic home, the person grieving over the loss of a spouse, the person disfigured in an auto accident or a fire, the infertile couple—when people like these seek help, are they really sick? No, they are not. But they do need help.

These conditions without sickness by no means constitute the total health picture of Americans, but they are a very significant part of it. Generally, most Americans are in good to excellent health by all the routine technical standards. Life expectancy is at a new record high. The average child born today can look forward to living 74.5 years, and even people my age are doing better on life expectancy. You and I can expect a few more years of life than our parents could at our age, and we can expect several more years than our grandparents could. I think these particular figures are more important to most families than the latest Dow Jones average.

Here is some more good news. The age-adjusted death rate for stroke, the third leading cause of death in this country, continues to decline. Today, the mortality rate for stroke is half what it was only 15 years ago, and it appears to be falling by about 5 percent a year. The same decline is occurring in heart disease, the leading cause of death in our country, although the change is not as dramatic.

Figures like these tell us that we are making good progress across a broad front of acute and chronic conditions. Yet I must tell you that none of this progress is based on new miracle cures, although some of it, very little actually, is due to new medical technologies such as coronary bypass surgery. No, it is because something else is going on in our society, something outside the domains of formal, traditional medicine. It is not any single thing, but rather a constellation of actions and attitudes that have captured the imagination of the American people. The self-help movement is a big part of it, with people joining together to provide emotional support to each other and to share information about common health concerns.

In light of these developments, I believe we have the answer to the first question, "What do we want to do?" We want to promote good health. We want to prevent acute and chronic diseases from occurring. That is the clear direction in which we are moving today—from almost total reliance on cure after disease starts to keeping it from starting in the first place.

What do we need to know to do it well? Certainly we need to have good biomedical science. That is crucial for both cure and prevention. But we need to know more—a lot more—about many things that are new to medicine. We need to understand more about human behavior; how people interact with each other and their physical environment; how they respond to life-cycle events such as childbirth, family growth, the maturation and departure of the young, and death. We need to understand how people cope with economic, social, and cul-

tural stress; how they perceive the future and how they see themselves as part of it. This kind of knowledge tells us not only about health, it tells us about wholeness.

How will we get this knowledge? From behavioral research? Yes, some of it. From research in medicine and the other life sciences? Yes, some of it will come that way, too. But I believe that a great deal of the new knowledge on health and wellness can come from groups like the ones represented in this workshop—from you.

Therefore my charge to you is to formulate recommendations around the following questions:

- How can we develop partnerships between self-help groups and the health care delivery system that improve the health and well-being of the public?
- How can we educate the public and the health professions on the use and benefits of self-help groups?
- How can we expand the current knowledge of how self-help groups work, their benefits and their limitations, through organized research?
- How can we begin to start and support self-help groups as part of a health care delivery system?

Let me make a suggestion about your responses to my charge. Naturally, I want you to consider issues and make recommendations that a Surgeon General has some chance of accomplishing, but I also urge you not to hesitate in making broader recommendations. The report of this workshop will go far and wide, and it is altogether possible that opportunities will come for me to make a fitting connection for you and your cause in areas where I have no authority to act directly.

I am delighted that this workshop is taking place. I am also pleased that the Public Health Service has helped make it possible and that a number of my colleagues from the Public Health Service are here to learn and share. I congratulate the planning committee not only for its good sense, but also for its sensitivity. The dynamic and independent nature of self-help movement people is indeed a virtue, but it is not always conducive to tranquil planning and organizing. The committee came through the crucible of planning with even stronger commitment to the goals of partnership.

My special thanks go to Mark Mayeda and his staff at the California Self-Help Center and to Marilyn Ruiz and Annette Nussbaum of the Illinois Self-Help Center for their very significant contributions to the workshop. Throughout the many months leading to this moment they have attended to countless details without losing sight of the overall objective, and they have been excellent coordinators.

Now it is up to the rest of us. Over the next 2 days, let us share our hopes, our knowledge and experience, our courage, and our love for who we are. We are people who know full well how imperfect the human race is but are nevertheless determined to make it better.

Let me leave you with these words by M. Scott Peck, M.D., from his book, *The Different Drum*:

> *There can be no vulnerability without risk. There can be no community without vulnerability. And there can be no peace, and ultimately no life, without community.*

God bless you. Thank you very much for coming. Now let us begin.

REMARKS OF THE HONORABLE JAMES R. THOMPSON

Governor of the State of Illinois

Dear Surgeon General Koop and Workshop Participants:

My congratulations and best wishes as you embark on the Surgeon General's Workshop on Self-Help and Public Health. I look forward to the results of your important explorations of the partnerships between self-help and public health.

Self-help has long been of interest to me and my administration. Indeed, we are very proud that one of the leaders in advocating for self-help and mutual aid is a well-known Illinoisan, Clement Stone. Stone understood very early how remarkable self-help could be—a voluntary effort through which people can help themselves while helping others—by sharing insights, problems, and support. Another Illinoisan, Leonard Borman, founder of the Evanston Self-Help Center, was one of the first people to sit on the Advisory Council of my Office of Voluntary Action. Borman was an articulate champion of self-help, and under his leadership a directory of self-help groups in the Chicago metropolitan area and a directory of self-help opportunities for people with developmental disabilities were developed.

It is important for people to know about the availability of self-help groups. In 1983, the Illinois Legislature made a grant available to start an Illinois Self-Help Clearinghouse. That project has included many partnerships—my office, the Clement and Jesse Stone Foundation, the Illinois Hospital Association, the American Medical Association, National Easter Seals, and many others. It is important that health care professionals and citizens be aware of the availability and effectiveness of self-help. Self-help has had tremendous impact in improving individual lives. In addition, it is a voluntary effort and is extraordinarily cost effective.

My best wishes for a successful workshop which will help all of us to help each other.

Sincerely yours,
James R. Thompson, Governor
State of Illinois

[1] Governor Thompson's statement was read to the workshop participants by Ms. Jean Bradner, Director of the Office of Voluntary Action, Office of the Governor, State of Illinois.

REMARKS OF THE HONORABLE GEORGE DEUKMEJIAN [2]

Dear Surgeon General Koop and Workshop Participants:

I would like to take this opportunity to welcome Surgeon General Koop and all the participants of this Workshop on Self-Help and Public Health. I am especially pleased that you have chosen the California Self-Help Center, a program initiated by our administration and funded by the California Department of Mental Health, for the site of your conference.

It is becoming increasingly evident that self-help groups are particularly effective in helping people cope with personal and health-related problems. The dramatic increase in the number of groups, both in California and throughout the Nation, has enabled thousands of individuals to seek the comfort and support of others facing similar concerns.

With representatives from self-help organizations, the media, human services agencies, educational and research programs, business, and labor, this national conference will enable the individuals with varied backgrounds to address the future of self-help in the United States.

I am confident that with your strong support and leadership, Dr. Koop, this workshop will be a success. Please accept my best wishes.

Most cordially,

George Deukmejian, Governor
State of California

[2] Governor Deukmejian's letter was read to the workshop participants by Mr. Clifford Allenby, Secretary of the California Health and Welfare Agency.

WELCOMING ADDRESS BY MARK MAYEDA

Workshop Moderator
Deputy Director of the California Self-Help Center University of California, Los Angeles

On behalf of the planning committee and the California Self-Help Center, I welcome Dr. Koop, other honored guests, and workshop participants. This Surgeon General's Workshop on Self-Help and Public Health is a historic event. Although it is only one step in gaining national recognition of the self-help movement and acceptance of the vitality of its principles, it is a major step.

All of us here today share an interest in self-help, but my perspective may differ from many of yours. I am a public administrator by profession and for the last 15 years I have been involved in managing not-for-profit organizations providing human services. As I gained experience in my field, I came to understand that an ever-present challenge is how to provide effective, quality services when resources are limited and needs for those services often exceed an organization's capacity to respond. It was only about 2 years ago, a year after I joined the California Self-Help Center, that I fully realized that self-help and mutual support presents an opportunity to meet this challenge. To understand why this is so, let me call your attention to some of the factors that make self-help groups so effective. My esteemed colleague, Dr. Bonnie Burstein, has identified three major things that these groups provide.

First, they eliminate the isolation of their members. When people develop a health or health-threatening problem they usually feel isolated and distant from those who do not have the same condition. However, groups of people who have a common problem and common experiences can end their isolation by sharing their feelings and giving each other needed emotional support. An example is SHARE, a breast cancer self-help mutual support group in New York. SHARE helps women cope with a highly distressing and physically difficult health situation. Members are able to deal with feelings that they have not been able to share anywhere else.

Second, members of such groups gain perspective by providing information on what can be expected emotionally, physically, financially, and socially, and much of this information is based on the personal experience of the members. Groups can also provide information on effective coping strategies. For example, I CAN COPE, a cancer self-help and mutual support group, helps its members understand what to expect from cancer treatments, such as chemotherapy and its side effects.

Third, self-help and mutual support groups help their members develop a sense of empowerment in situations that usually create feelings of helplessness. The sense of empowerment comes in two ways: seeing others cope with the same concern, and helping oneself by helping others. The California Network of Mental Health Clients and the National Black Women's Health Project are examples. Both use self-help mutual support groups

to develop in their members a sense of empowerment and control of their own well-being.

Fourth, self-help and mutual support groups are able to reach not only those who are directly afflicted but also those who are close to them.

These attributes of self-help and mutual support groups can have important consequences for public health, and in my view they support the validity of seeking partnership between the self-help movement and the health care delivery system. However, I must also stress the importance of respecting the integrity and autonomy of the groups. The full value of self-help and mutual support groups is possible only because they are self-Governing and serve the needs of their members, not those of outside powers.

There is much that all of us need to learn and understand about self-help and mutual support. We face formidable challenges over the next 2 days and well into the future, but I am confident that we are equal to the task.

WHO WAS INVITED HERE—AND WHY

Frances Dory
Member of the Selection Subcommittee and
Executive Director of the New York City Self-Help Clearinghouse

Hundreds of people were nominated as potential participants in this workshop, and to have invited them all would have made a conference far too large to operate effectively. Though we had selection criteria, it was no easy matter to sift through these nominations. Your presence here means that, in the opinion of both the selection subcommittee and the larger planning committee, you best represent the self-help movement in America today.

You bring a wealth of experience and knowledge that we need, and we respect and appreciate your commitment to apply that experience and knowledge to improving the well-being of the American people. We know how difficult it was for some of you to get here, and we thank all you for coming.

There are 175 of you here from 23 States and the District of Columbia. You are equally divided between men and women and between human service providers and self-helpers, and 27 percent of you are members of racial minorities. A substantial number of you are people with disabling conditions, and you are a very significant part of the self-help movement. This diversity is essential to the work we will be doing over the next 2 days, and it will be reflected in the composition of each of the smaller topical groups to which all of you will be assigned when we get down to the business of this conference.

Now I want to tell you a little story. It's about a man named Sam who died. On arriving at the gates of Heaven he petitioned St. Peter, who was surrounded by a host of angels, to let him in. St. Peter informed Sam that he would first have to make a brief presentation about his qualifications. Unfortunately, Sam had

not participated in any self-help groups and therefore was not fully prepared to deal with this level of disclosure. He said he would have to think a bit before he could come up with something St. Peter might find acceptable. St. Peter, being a good helper, encouraged Sam to reflect on his life and recall some event that could provide convincing evidence of his eligibility for admission, then left him alone to ponder.

When St. Peter returned after awhile, Sam told him he thought he deserved to be in Heaven because he had survived a great flood in Johnstown, Pennsylvania. St. Peter, bewildered, asked him to explain why that should be a qualification. "Well," said Sam, "that flood came when I was a boy, and it was scary, there was a lot of damage, and a lot of people died. But I survived it, and that's why I think I should go to Heaven." After a long pause, St. Peter motioned toward the band of angels and whispered, "Sam, I think I ought to tell you, Noah is in the audience."

We who organized this workshop understand how Sam must have felt at that moment, because all of you in this audience are Noahs. Yes, we did work hard, but we are mindful that we are building on values and traditions that have been carefully and deliberately thought out by people like you, who have worked hard over many years and know what it's like to be in a real deluge.

The self-help movement is diverse and not especially well organized, but it is not haphazard. Since the founding of Alcoholics Anonymous more than 50 years ago, self-help groups have proliferated at a phenomenal rate. Ten years ago, the President's Commission on Mental Health set the stage for the interface of formal health care systems and informal helping networks by recommending the development of resource centers to collect and disseminate information on self-help groups. These centers, many of which are now known as self-help clearinghouses, have added immeasurably to the proliferation of support groups in their geographic areas. There are now more than 40 of these clearinghouses in the United States and several in Canada, and linkage between self-helpers in different countries was established just 2 years ago with the formation of the International Network of Mutual Help Centers.

Today we begin another leg of this journey of pulling our movement together, making it better organized and more effective, and becoming clearer about what we want and need. No matter whose figures you use, there are more than 10 million people who regularly participate in mutual aid groups. By any standard, when that many people are doing something in essentially the same way and out of the same belief system, what you are witnessing is a social movement. Like the women's movement and the civil rights movement, we are part of an effort to create social change in America, and like all such movements, our goal is to improve the relationships among people.

What the self-help movement is about is better relationships in the spiritual sense. It is about the changes needed in human services agencies to make them more effective, more accountable, and more meaningful to the people they hope to serve. In this new leg of our journey, we have to do more than look at those whom we serve now. Some of the unmet needs we will be addressing in the next couple of days involve huge numbers of people who are not being served. An estimated 22 million people in this country have hypertension, but not many of them are being served by self-help groups at this

time. It is also estimated that there are 6 million substance abusers, 5 million diabetics, and 18 million arthritics. I am sure Dr. Koop could tell us about the number of people who still smoke, and about the lung diseases and other disorders they risk or have because of it. Self-help groups exist for all of these conditions, but most of the people who have them are not yet participating.

The task we face is enormous, because the number of people who are not being served is enormous and that number keeps growing. For example, 10 years ago acquired immunodeficiency syndrome was unheard of, but today most of our self-help clearinghouses are dealing with the huge task of reaching out to people who test positive for HIV, to those who actually have AIDS or AIDS-related complex, and to those who are struggling to give them care. We believe that self-help has enhanced the services available to all these people.

These tremendous unmet needs can be met if we can tap the tremendous human potential represented by the very people who are having the problems, yet too often those people are seen as problems, not as resources. You and I know that every person who has arthritis, diabetes, AIDS, or any other condition is a potential caregiver capable of helping others resolve, cope with, and change the conditions of their lives.

This entire society cries out for new definition of the ways people relate to each other. The essence of right relationship is seeing ourselves as part of the solution and recognizing that none of us is safe from tragedy. Levine's phrase, "the soap opera of life," applies to all of us. We are not at this workshop to talk about what we in here can do for them out there, we are here to talk about how all of us in this society can save ourselves by helping each other. That is our hope—that we can begin to see ourselves as a community and as part of a very, very important movement, and perhaps its cutting edge.

WHAT HEALTH PROFESSIONALS CAN LEARN FROM BREAST CANCER PATIENTS

Leonore Miller
Member of the Planning Committee and
President of the SHARE Breast Cancer Group
New York, N.Y.

Twelve years ago, I could not have imagined that anything positive could come from having breast cancer. Now, looking back, I can say that out that frightening and devastating experience some rewarding outcomes did emerge, namely my involvement with SHARE, a self-help group for women with breast cancer.

We began 11 years ago, inspired by Dr. Eugene Thiessen, a concerned physician who felt that breast cancer patients, especially younger women, needed to discuss their concerns with their peers. Though he was a physician who had the sensitivity to see the painful emotional aspects of this disease, Dr. Thiessen was nevertheless a frequent target of anger among the

women, as a symbol of all the surgeons who were perceived as having massacred and disfigured us.

Over the past 11 years I have listened to the experiences of more than 600 women. All of them were unique individuals, but the fear, the anger, the depression, and, yes, the hope they expressed was universal. Through floundering and trial-and-error learning we learned ways to cope with this life-threatening illness and its emotional, social, and practical impacts. We each brought our own history to our illness, so we all reacted differently to it, but always consistently with the core of ourselves.

Hippocrates said he would rather know what sort of person has a disease than what sort of disease the person has. Listening to each other and sharing our differences gave us the ability to appreciate our basic similarities and thus validate ourselves. Watching others nod their heads in affirmation as we spoke was more comforting than a thousand words from someone else who did not truly understand. Sometimes when a new member arrived, tears of relief would flood her eyes because at last she could allow her feelings to surface in an atmosphere of encouragement and warmth.

At that time, radical mastectomies were the order of the day. Breast reconstruction was not on the scene yet, and involving the patient in medical options was still in the distant future. Lumpectomies were considered poor medicine, and power between the women and the medical establishment was very unbalanced. It was not until 1979 that insurance companies stopped classifying breast reconstruction as cosmetic surgery and began to reimburse for it, although they had always reimbursed for testicular implants.

These changes were accomplished by women who became knowledgeable medical consumers, who began to regard themselves with confidence and trust and to feel their own power. Mutual aid groups were instrumental in fostering this spirit, because when women came together in an atmosphere of trust and acceptance, their collective experience gave flesh and bones to theory, and the subjective become something visceral. This understanding needs to be communicated to health care providers through networking, informal meetings, informational materials, and the personal self-help experience a health care provider might have encountered.

Many women feel shame and guilt because they have cancer. The very word evokes the thought of death. An attentive health care provider can diminish guilt and shame and reinforce the idea that cancer carries with it no moral implications or judgments. The altered body image does create problems regarding desirability and sexuality. But before discussing sexual matters with patients, health professionals should be comfortable both with the subject and the colloquialisms used to discuss it, be prepared for all types of questions, be nonjudgmental and supportive, include the partner whenever possible and without assuming that it is always a male or that there even is a partner, have a quiet private place to talk, and really listen.

Two national surveys indicated that the three main determinants of patient satisfaction are all related to contact with the physician. Most important is the initial contact, then the information conveyed, and finally, the general supportiveness. Physicians are trained to cure. They are used to success and want to be superhuman, but cure is not always possible or certain. Physicians who cannot handle their own feelings in this situation may

withdraw just when the patient is most in need of support. Training in medical schools and hospitals is needed to help physicians deal with their own feelings about death and lack of success.

Health care providers need to keep up with the latest developments in the field, both to diminish their own pessimism and to avoid cutting off hope in their patients. Nurses have the most intimate contact with patients and the greatest opportunity to pick up clues and communicate with warmth and understanding. But being female, as most nurses are, has its own special problems in caring for breast cancer patients. Nurses may be constrained by their identification with the patient and their own fears of illness and death. If a nurse has had breast cancer she must be careful not to react in terms of her own disease, but in terms of the patient's needs. Coping strategies for stress and burnout need to be considered for anyone working with high-risk patients.

The sensitivity of professionals in their relations with patients was a topic that came up many times during group meetings. I can remember lying on a table in a huge chilly lab, waiting for the results of a lung biopsy. The technicians had a few idle moments while the test was being done to see if my cancer had metastasized to my lungs. They began to chat and joke and laugh among themselves while I lay there trembling and waiting for the news. It was Friday afternoon, and as they talked about their plans for the weekend, it made me feel acutely that I might never be part of that normal world again. I was too frightened to speak up and ask them to stop, yet I also understood that they were expressing their own need for release from tension. Fortunately, the results were good, but later, when I knew more and heard similar stories from so many other women, I was sorry I had not used the opportunity to point out to them how that kind of banter exacerbates a patient's anguish.

One of the women in our group was frightened of her chemotherapist. He seemed impatient when she asked questions and he often engaged in long phone conversations during her treatment. But she also felt that her life depended on him, and she was afraid of retribution if she were to make her needs known. The women in the group tried to encourage her to speak up, and one of them volunteered to accompany her on the next visit and give her support in confronting the physician. The two women did go together on the next visit, and although the SHARE volunteer said nothing, her mere presence improved the situation. The doctor did become more cooperative and his telephone conversations did become shorter.

Trust in the doctor is a prime requisite for creating a receptive environment for treatment, but a trusting relationship implies that patients feel it is safe to criticize. How contradictory it is when a physician responds with professional skill to save a woman by surgical or medical intervention, then denies her the support she needs to form a different lifestyle and adjust to an altered body image, and the woman—frightened and depressed—is unable to say anything about it.

Out of the hundreds of meetings of our group over the past 11 years a body of subjective knowledge has emerged, through groping and pain, trial and error, sharing and laughter. I want to summarize what we have learned, because I think it provides a true grasp of what self-help is all about. Furthermore, I think it can lead to a real partnership with the formal health care system that is built on a bedrock of understanding.

- Fear, anger, and depression are normal responses to a serious disease.
- There is solace and validation in sharing with peers.
- Grieving is healthy because it frees up your energy to get on with your life. But grief comes in layers, and each layer must be worked through or it goes underground and emerges in undesirable ways. One woman told us that after mourning the loss of her breast she was able to grieve about the loss of her father, then her divorce, and finally, the loss of her pet.
- Facing the possibility of death means losing your feeling of invulnerability. It is much like losing the innocence of childhood. But facing reality can enhance the good times, change your perspective, and establish your priorities. You become able to ask questions like, "If not now, when?" and the social hypocrisy most of us indulge in from time to time seems superfluous.
- We need to feel in control again, even if we know it is an illusion in the grand scheme of things. We need to feel we can take charge of our own bodies, be informed medical consumers, and participate fully in decisions regarding our health. An uninformed choice is not a real choice.
- We are more alike than different, but we need to appreciate and respect our differences.
- There is a difference between enlightened self-interest and selfishness.
- Living with uncertainty is difficult, but it is possible. Having cancer taught us what was always true, that life is uncertain.
- There are many kinds of courage, and though we cannot absorb courage from others, we can be inspired by it.
- Each of us is a person of value, and when we respect our own essential humanness, we can bring that respect to others.

For me, that is the message of partnership. This workshop is a special moment in time—a time for self-helpers and health professionals to reflect and join hands to fight our common enemies, ignorance and disease.

WHO WAS INVITED HERE—AND WHY

Frances Dory
Member of the Selection Subcommittee and
Executive Director of the New York City Self-Help Clearinghouse

Self-help clearinghouses represent one of the most exciting and innovative forms of human service today. Over 40 of them have been created across the country in the last decade, and each of them has been finding new and different ways to foster the development of self-help groups in their communities and increase awareness of their availability by people in need.

These clearinghouses also serve as bridges for increasing collaboration between the self-help and professional communities. Through their work they

demonstrate some of the possibilities that exist for any organization to collaborate with self-help groups in meeting people's health and human needs.

Our experience in New Jersey is just one example. At our medical center, it all began with a simple list containing contacts for some two dozen self help groups. It had been compiled because several hospital staff members had often asked for these hard-to-find resources and were reporting how grateful patients were to learn about them. The more the list was circulated, the more it grew, until it eventually included nearly 70 groups.

As we followed up on leads, we began to come in contact with people who had wanted to start a group but didn't know how to proceed—people like Elinore Neal of Reach to Recovery, who said, "I don't want to start this mastectomy group for myself. I simply want to prevent other women from having to go through the hell I've had to go through alone." We linked people like Elinore with all the related national or model groups we could identify, so they wouldn't have to reinvent the wheel. We eventually published this list as a directory that included national groups that had no local chapters, so people could see what new groups might be started in their community.

We had observed what we refer to as a demonstrational effect, and we saw its power to encourage people to start new self-help groups in their communities by providing evidence that a similar group had been started somewhere else. For example, we had numerous calls requesting information on groups for survivors of suicide. No such groups existed in New Jersey, but we were able to send callers material from a model group in the midwest. One woman called back in tears, explaining that the material had shown her how starting such a group could provide meaning to a meaningless act.

Hospital staff expressed an interest in helping patients form new groups. A laryngectomy club was started with the help of the speech and hearing clinic staff. The mental health center's phobia program staff assisted in developing an independent phobia self-help group for patient aftercare support.

As time went on, more and more lay people called seeking a group, and if there was no group to refer them to, we would simply ask them if they would be interested in joining with others to form a group. We recorded the names of those who said yes so we could link them with the next caller who might also be interested in developing that particular kind of group. It was like rubbing two sticks together to make a fire. Those linkages often resulted in new groups. We began to realize how, with a little encouragement and support, some of the help-seekers who called us could be readily transformed into resource developers who started groups.

We have found that one of the most appropriate roles we or other professionals can take in helping these groups is that of consultant, giving advice and counsel but not getting involved in actual decisionmaking or leadership. In our view, the professional should remain on tap, not on top.

In 1981 we extended services to the entire State using toll-free phone lines and a computer system that included a local, State, and national directory. Since that time, by providing encouragement and support, we have assisted in the development of over 420 new groups across the State. We have given consultation to people like Nancy Berchtold, who called us 2 years ago to ask about a group for postpartum depression and found that there weren't any. She went on to develop one

of the first such groups in the country, and it has since grown into a national organization helping many more groups get started. Then there are Sally and Jeff Toughill, who founded the Histiocytosis-X Association of America to work with and learn from other parents of children with that condition.

Clearinghouses have helped start many groups across the country that have developed into State or national foundations. We should recognize that many long-standing health foundations, societies, and agencies dealing with specific illnesses began as self-help groups. This form of development continues today as improved medical technology and research increase the survival for previously life-threatening disorders and continue to identify new disorders.

In 1984 a blind caller educated us about the need for special self-help groups for people who were losing their sight. We worked with him and wrote a proposal that provided him with a driver, a staff, and a position at the clearinghouse. His name is John Dehmer, and he and his staff have started over 30 new self-help groups across the State for people who are visually impaired or adjusting to blindness.

In other development work, the clearinghouses use self-help group representatives as paid part-time consultants for education and training. Our clearinghouse currently helps over 10,000 callers a year with referrals; over a third of them are professionals who have no other place to turn. We also publish a State directory each year along with newsletters and various how-to materials, and we assist in conferences and workshops throughout the year that bring professionals and self-help group leaders together to learn from each other. Foundation-funded grants have allowed the creation and distribution of Tel-Med tapes on self-help for every hospital in New Jersey and the publication of a national directory of groups.

Still there is a great need for learning. It was Marie Killilea, speaking at one of our New Jersey conferences on self-help, who wisely counseled us that the first thing professionals have to learn about self-help groups is that there is something to learn. Although professionals have become increasingly aware of the value of self-help groups, few understand the underlying principles of self-determination and empowerment that are fundamental to their life and success. By understanding these principles, professionals and self-helpers have a better appreciation of how to form partnerships without compromising the essential nature of self-help.

I believe the most important need is to respect self-determination. Several years ago I asked Dr. Agnes Harfield, a researcher who is one of the founders of the National Alliance for the Mentally Ill, what she felt was the most important factor that contributed to the vitality of a successful self-help group. Her reply was one word: "Ownership." A sense of ownership on the part of the members. To the extent that the members recognize that the group is theirs, they will invest their time and effort to make the group work. But if they perceive that the group is owned by someone else, whether a professional or an agency, they tend to step back and let the professionals do the work.

In negotiating any partnership it is important to have a true sense of equality and mutual respect for each other's values and knowledge, whether that knowledge is experiential or professional. A partnership is built between equals. Self-help groups empower their members to regain control of their lives and deal effectively with their condition. They

encourage individuals to assume an active role in restoring and maintaining their health. Some groups are advocacy oriented, reflecting a healthy skepticism of our health care delivery system and helping to make health care more responsive to consumer needs.

Several self-help groups have shown their ability to improve public health on at least three other levels of health care delivery. First, they have demonstrated their ability to prevent some health problems from occurring by reducing stress in general, as well as through educational programs such as laryngectomy clubs, stop smoking campaigns in schools, and certainly the advocacy efforts of Mothers Against Drunk Drivers (MADD). Second, they have shown that they can supplement and humanize treatment services by serving as adjuncts to treatment or providing social support and help that is not available within the professional milieu. Third, they have demonstrated their ability by providing aftercare services that reduce recidivism, reinstitutionalization, and readmission to the health care system.

There are some areas that require development. From our experience, the media clearly have tremendous power to inform people about self-help. We saw that in the case of a woman who called us after seeing a television program about incest. She told us it had been 40 years since she had been abused by her father, and she had never spoken to her husband or her therapist about it. The TV program, which depicted a self-help group, had given her the courage to reach out to someone else. We can do much to maximize media resources, from promoting weekly newspaper listings of groups to developing public service announcements.

Advances in telecommunication provide additional opportunities. Telephone and computer conferencing systems have permitted an increasing number of self-help groups to meet over great distances. Our clearinghouse has helped host telephonic meetings of people with Ehlers-Danlos syndrome, a connective tissue disorder. It was the first opportunity they had to talk with other people who had their condition, and several of them went on to form a national foundation for the problem.

Health care and other agencies can play a role in making this technology more available to self-help groups, for reaching out to rural areas, and allowing participation by people who are unable to leave their homes or their hospital beds. Electronic communication will surely increase the linkage of people, ideas, and concerns in the years ahead and will provide many innovative ways for people to find and develop the mutual aid and support they need.

Local self-help clearinghouses and resource centers, which now serve almost half the country, have their own stories to tell about the partnerships they have helped create and the ones that remain to be created. The International Network for Mutual Help Centers, an association of centers that was formed in 1985, serves as a forum for the development and exchange of these and other ideas that support the philosophy and practice of self-help. Members of the network may be of service in implementing some of the recommendations that come out of this workshop.

All of us here realize profoundly the immense potential of self-help groups, and we know that more must be done to make health care professionals aware of these resources so more people can find the support and the help they need. We recognize that it would be unethical for a physician to withhold the medication a

patient clearly needs. With the increasing amount of research that indicates the value of social support in restoring and promoting health, we must ask ourselves if professionals do not have a similar obligation to provide patients with referral to self-help groups when they know it can reduce suffering and promote recovery or rehabilitation.

SELF-HELP FOR HEALTH PROFESSIONALS

S. Denise Rouse
Member, Planning Committee
Board Member of the National Black Women's Health Project Commissioned Corps, USPHS

Like many others, I came to the self-help movement seeking an alternative. I was dissatisfied by the lack of progress in improving health in the black community. I knew that most black Americans had some access to health care, but I was also aware that it wasn't making much of a difference. Knowing that the major causes of excess morbidity and mortality are behavioral, I chose to look outside the system.

My search led me to the beginnings of the Black Women's Health Project of the National Women's Health Network, which later became the National Black Women's Health Project, Inc. This is a self-help organization whose purpose is the empowerment of black women around issues of improving their own health status, and its major intervention strategy is the self-help group. Supporting strategies include developing health promotion material oriented to black women—films, videos, brochures, newsletters, and conferences—and developing a body of accurate information about black women for use in forming public policy.

I came into this movement with the notion that I would find a tool that would enable me and others to improve our health. What I also found was a way to improve my own life. I also learned that, for most people, it is not what is done to them that makes a long-term difference in their lives and in their health, but what they can do for themselves.

Shortly after becoming involved in self-help, I was reassigned to West Alabama Health Services, a rural health care delivery system in Alabama. With the gracious and generous support of Jim Coleman, the executive director, and Sandra Hewlett, the medical director, we began to test self-help as a tool for improving health status, using the self-help model developed by the National Black Women's Health Project.

We started staff groups first as a way to validate the appropriateness of using self-help as a tool for health promotion, with additional goals of improving communication among the staff, enhancing their sensitivity and responsiveness to clients, and improving staff-client communication. The self-help groups for staff were organized in three settings—an ambulatory care center, an infant survival project, and a nursing home. The participants, who self-selected after the project was presented to all staff members, represented all but one of the profes-

sional and nonprofessional staff categories. The only category not represented was dentistry. The staff groups started in November 1984, meeting weekly for six months, then every two weeks. The average membership was 19 and the average attendance was 10. These groups dealt with workplace issues, personal health problems, and family problems.

The long-term care facility was in a state of crisis when we formed a self-help group there. West Alabama Health Services, which is a federally funded primary health care center, was in the process of developing a health maintenance organization for the Medicaid population as a demonstration project. The county hospital and nursing home were on the verge of closing, and since their closure would have ended the development of the health maintenance organization, that organization took over their management. The nursing home was in danger of losing its license because of the quality of the care that was being given to its residents. Self-help group techniques were used in managing the staff during this crisis and in reshaping the staff into an effective long-term care delivery team. The nursing home retained its license and patient care improved dramatically.

The issues addressed in the long-term group were feelings of oppression by management, inability to cope with a rapidly deteriorating and demanding workplace, low morale, perceived racism in work relations and in patient care, dissociation of the staff from the residents, and the problems of coping with disability, dying, and death on a daily basis. The self-help group also supplied motivation for staff in a setting where financial incentives were lacking.

We found that staff members valued the opportunity to have input in decision-making, to share relevant experience and expertise with management, and to be recognized for the first time as valued and respected members of the health care delivery team.

From our experience with the staff groups, we concluded that the model was indeed appropriate for our clients and proceeded to form a young mothers group. These were first-time mothers, which in that community means teenagers. The participants were also participating in an infant survival project funded by the Ford Foundation. During the group's first year there were no infant deaths. The group, which called itself "Sharing Good Values," began a loan fund to alleviate the shared experience of not having enough money to get through to the end of the month, raising money for the fund by organizing dances and rummage sales. Group members were able to deal openly with such sensitive issues as contraception, teen pregnancy, sexually transmitted diseases, breast cancer, obesity, and family violence. This was possible because the self-help process alleviates feelings of isolation, powerlessness, and hopelessness, which affect behavior profoundly. Sharing occurred in an atmosphere of trust and acceptance that many of these young women had never experienced in their daily lives.

The National Black Women's Health Project has found that self-help groups are very effective in bridging the gap between the public health community and the black community. Felicia Ward, a self-helper in Oakland, California explains that the reason lies in the process of empowerment. Individuals recognize their own need to change and want to share their experiences with others, so they form a group. The group in turn wants to share what it has learned with the entire community. This progression

from the individual to the group to the community is a normal, natural flow of information that has been validated by the leaders in the community.

In Georgia the National Black Women's Health Project uses their model of self-help group development to mobilize women to participate in a series of maternal and child health conferences sponsored by the Georgia Department of Human Resources. In North Carolina five self-help groups formed the bone and sinew of a statewide health planning network that has established a historic linkage between North Carolina A&T College of Nursing, the NAACP, the North Carolina Child Development Institute, and grassroots women. Similar networks now exist in South Carolina and California. In California the South Berkeley Women's Center is using the self-help group as a tool for helping women cope with their health problems.

I believe the beneficial effects of self-help on public health are infinite. I will mention just a few. Self-help breaks down the communication barriers between providers and clients by creating an environment where greater trust is possible, where the client can be viewed and understood as a whole person. It provides a process for translating health information into a usable form, frequently by the clients themselves. It builds bridges between public health and the community and provides a mechanism to get information to hard-to-reach groups, and this is critical for implementing community-based health promotion programs. It offers providers additional tools for coping with an ever-changing and demanding workplace. It offers providers insight into their own frustrations about noncompliant patients. Self-help provides an opportunity for providers to share their knowledge and expertise in a receptive, nonthreatening atmosphere. It can be a tool for resolving sensitive issues and conflicts in the workplace. It can give providers a tool for coping with their own responses to disability, death, and dying, and this is especially relevant in long-term care settings and in caring for AIDS patients.

In the six years I have been involved with self-help I have learned six lessons:

1. The self-help process is particularly effective in dealing with isolation, powerlessness, and hopelessness.
2. It is effective in enabling people to cope with many forms of oppression, whether by society, by individuals, or from within.
3. Health information is more valued when it is delivered by a provider who has experienced a health problem first-hand and can share that personal experience.
4. Self-help principles are highly adaptable to different sexual, racial, and cultural groups. For example, the National Black Women's Health Project has successfully shared its self-help model with Kenyan, Caribbean, and Latin American women. Each community adopts from the self-help process what they feel will work for them.

   As health professionals we need to respect each group's ability to shape the self-help process for its own needs. This implies acceptance and respect for cultural diversity.
6. It is important to understand one's own health concerns and behaviors before requesting others to change. By going through the self-help process first, professionals gain valuable insights as well as credibility.

I believe that a partnership already exists between self-help and public health.

In some of the federally-funded migrant and community health centers, for example, self-help projects have been implemented for infant mortality prevention, teen pregnancy prevention, diabetes control, and improved nutrition. My favorite example is the "brown bag" program of the Delmarva Ministries Migrant Health Center in Delaware, in which women in seasonal and migratory farmworker communities pool their limited food money to make lower-cost bulk purchases from a local wholesaler.

The self-help process is particularly adaptable to the needs of rural and underserved communities and migrant and seasonal farmworker populations because of its ability to end isolation and its marvelous adaptability to ethnic differences. This is especially relevant for the migrant community, both because it is migratory and because there are at least five different ethnic groups harvesting the Nation's crops at any given time. The National Migrant Health Program of the Public Health Service has, for the first time, a national program objective to encourage the development of a self-help component in the health promotion programs of all 122 migrant health centers.

In summary, self-help offers two major benefits to health providers: it helps us cope personally with the work environment, and it helps us serve our clients. In addition, it provides tools for program management and mechanisms for working with hard-to-reach and culturally diverse populations. The self-help movement provides a marvelously adaptable tool for health promotion. I encourage health professionals to take the time to understand the process fully by experiencing it first-hand.

THE POLITICS OF SELF-HELP

Irving K. Zola
Professor of Sociology, Brandeis University
Co-Founder of the Greenhouse Mental Health Collective
Co-Founder of the Boston Self-Help Center

There was once a health worker who was standing by the side of a raging river. Suddenly she saw someone floundering desperately in the turbulent water, about to drown, and she jumped in and pulled him to safety. She had no sooner restored the victim's breathing by artificial respiration when she heard another cry of distress coming from the river. Again she jumped in and rescued someone on the verge of drowning. This went on repeatedly. As soon as she would save one life there would be another one to save, and another, and another. The health worker spent so much time jumping into that raging river, dragging out its victims, and applying artificial respiration that she had no time to see who the hell was upstream pushing all those people in.

I want to talk about certain kinds of self-help activities that are intended to prevent people from being pushed into or falling into that deadly river. For lack of a better term, I call it the self-help movement's political function. That function has always been a major part of the movement. Katz and Bender, in their extraordinarily fine history of the self-help